



Community Self-Help Education Series no 7

Let's start our own Community HIV/AIDS Support Group



Resources Manual

Shortened quote from The Universal Declaration of Human Rights:

Everyone has the right to a standard of living adequate for the health and well being of himself and his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or lack of livelihood in circumstances beyond his control. (25.1)

By Arnfinn Solli

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Acknowledgements

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HIV and AIDS

HIV and AIDS are not the same thing, though they are extremely closely connected. HIV stands for Human Immune Deficiency. This is the name of the virus that is transmitted, through body fluids, from one person to another. The virus can reside in a person for numbers of years without being noticed or felt.

So someone who is HIV positive can be strong and healthy at first. But, without treatment, the virus eventually wears down the immune system of the body – the system that helps the body fight off diseases. When this happens a person is said to have AIDS (Acquired Immune Deficiency Syndrome). This is the final stage of the disease. People who have developed AIDS have very little resistance to other diseases.

In this book the term HIV/ AIDS is used in all instances when referring to people who have HIV alone or who have the HIV virus and who have developed AIDS. The term HIV + (HIV positive) is used when referring specifically to people who have not yet developed AIDS but who have been infected with the HIV virus.

This paragraph is quoted from the book “The Church in an HIV+ World”

How to use this manual

The manual is intended to serve as a tool for Church and community leaders that intend to improve caring for the HIV/AIDS patients in the community.

You do not need to have education or money to make the first steps. A heart for the caring of the HIV/AIDS patients in the community will be enough qualification to make the first step.

Use the feet and go around to offices that might assist you.

The usefulness of the manual is by guiding about what office to go to and what service to ask for at that particular office. If they for various reasons cannot give

[illegible]

you the service you went for, ask them to advise you on alternatives or other places you can go and get that support.

Forge partnership with other people in the Church and community who know more than you and can fill in where you come short. For instance, when you need to make contacts to organise support to the HIV/AIDS support group, ask the families in the Church and community for small donations to pay for stamps or important phone calls or send e-mails. When you need to write an application for support or funds, ask the teacher or a Church leader to write the letter for you. Request the Internet café staff to help you to send an e-mail if you do not know how to use a computer.

When you need to start the HIV/AIDS support group at the local Church, make the point by reminding them that the beneficiaries from the HIV/AIDS support group activities are the families in their own Church and community. The HIV/AIDS support group is enhancing the Church and community's efforts.

Basically, this manual will enlighten you about some of the opportunities that exist in Zambia for assistance to HIV/AIDS support groups; both the volunteer members of the support group and the welfare of the HIV/AIDS patients that the group is targeting.

There are many offices, institutions and organisations that has among its objectives, an obligation to provide services to HIV/AIDS prevention and caring initiatives. However, due to insufficient funding and staff training some may not always be effective in their outreach.

You, as a concerned Church or community member will be valuable to these organisations by asking for their assistance so they learn about the real needs of the HIV/AIDS support groups in the communities.

The HIV/AIDS patients need assistance

There is a challenge, there are too many HIV patients in your neighbourhood that are not receiving the assistance they need of empathy, understanding and care due to lack of information about how to start and find support to a HIV/ AIDS support group.

You may ask: Is it possible to start a HIV/AIDS support group when we have no money? You may reply that it is impossible without money.

In the village in the old days, caring were the responsibility of the extended family. However this system has been eroded by the flight from the villages into the towns. Still the caring traditions are in peoples' minds and may now be carried on by volunteers serving the Church and the community. Furthermore the caring challenges of the HIV pandemic are overburdening the extended family, as the scale of people infected and affected is massive.



It is possible to do a lot provided that you can mobilise volunteers in the Church and community and build on the good will of volunteers and only depend on local resources for a start.

The First Steps

"God helps those that help themselves"

Some people say when seeing half a glass of water: "The glass is half empty", they look at it from a negative point focussing on what is missing, others say "the glass is half full" and focus on the positive that still there is plenty of water!

We are aware that running a HIV/AIDS support group is no easy task, however, we want you to look at the bright side; the glass is half full, - therefore this resources manual

will guide you to look for a lot of opportunities for assistance that the HIV/AIDS support group might access from various sources locally or internationally.

It is common to find a key person or a small group of people within a local church who have a burden about HIV/ AIDS and are interested in initiating a church HIV/ AIDS programme. Such people are often passionate about it but have no clue about how to put their ideas into meaningful actions so very little, if anything actually happens. This can be frustrating, and we might feel guilty about not having responded effectively to what we have understood to be God's call. This section offers a few guidelines for getting started.

Step 1: Learn as much as you can about the disease

Acquire some basic information about HIV/ AIDS and its implications before pursuing the vision further. You may also want to connect with people in other churches who have projects running to learn from them.

Step 2: Share your vision with your church leaders

This could be your minister, the church/ parish council or any other influential person within the church. Use the information you obtained in Step 1 to help you argue why you believe it is important for the church to develop an HIV/ AIDS support group.

Step 3: Recruit interested people

People are your most valuable assets! You will need to bring them in to a planning team that will help drive the process, and you will need them to do the "Frontline" work, doing the actual awareness raising. Usually, these people will be working as volunteers.



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You are free to make copies and share the information with anybody that wishes to know more about the right to education. However, we appreciate that you tell where you found the information.



To identify suitable people to do the practical work, think of different people who are already actively involved in doing similar work. Community volunteers might be working on their own and would appreciate your support. Support might include offering access to appropriate training, resources to improve what they are doing, etc. in exchange, such volunteers would need to report on their work and assist in liaising with other structures in the community. It is important to involve people with experience as group members. But be careful not to ask people who are already very busy, as they might not be able to give as much time as is necessary.

It is important to try and involve individuals who share the same vision. A lot of time and energy is wasted when people of different ideas and views embark on such a programme. It is better to work with a few people who are committed to their work and whose values are similar to yours. For example, if you believe that the most important thing is to reach out with compassion to those living with the virus and their families, it is no good to link up with someone who believes that people with HIV have only got themselves to blame and should first and foremost be told to repent!



Step 4: Ensure that the support group members receive training in HIV/AIDS

Every member should be equipped with basic information about the disease and its social, economic and cultural implications.

Step 5: The Support Group

Many projects have failed because a few people have decided what are needed and gone ahead and done things without consulting with ordinary people.

The group needs to start by spending a lot of time brainstorming how to go about this and who to consult. It is important that everyone in the group feels equally involved in defining what is important otherwise conflict can arise. Enough time should be spent on deciding what aspects to focus on, and then the team should stick to those.

It is important not to focus on too many dimensions at a time, as you could become overwhelmed.



One aspect at a time is best (or perhaps two interrelated ones, such as home based care and counselling). This will help establish and develop the planning team's vision and ensure that you have enough resources, both human and financial, to do it well. Once you have chosen an area of focus, acquire as much information on that particular aspect of HIV/AIDS as possible. Then involve

PLWHA if they have opened and are available in your district

Step 6: Decide on structures that will enable you to be most effective:

There are several decisions that need to be made here, especially because of the importance of networking with other players (both in your church and in the community) in order to be effective. Network from the start, but once you get established it becomes even more crucial to share information and resources with other parties so as to offer a holistic response to this pandemic. Remember that this is not competitive work but collaborative ministry. Even though you may only have the capacity to deal with one or two aspects, if you network successfully you will be able to refer people to other projects for help in other areas they might need.

about sources for support to education in communities in Zambia that need to know more about their human rights. However the concept can easily be adopted anywhere in the world where there is no school by rewriting the manuals in the relevant local official language and feature the support structure in that country.

If you are looking for more manuals, you can write to or call Response Network, Nkumbi Road, Plot 936, near the ZAWA offices Livingstone. Fax:0213 323 634 and Tel 0213 320491. Or write to P.O.Box 60817 Livingstone.

The UN declaration was adopted by the United Nations. Zambia has signed the declaration. The following is a selection of some of the articles (shortened) of the human rights:

- *All human beings are born free and equal in dignity and rights. (1)*
- *Everyone has the right to life, liberty and security as a person. (3)*
- *No one shall be held in slavery or servitude. (4)*
- *No one shall be subjected to torture, or inhumane or degrading treatment or punishment. (5)*
- *No one shall be subject to arbitrary arrest, detention or exile. (9)*
- *Marriage shall be entered into only with the free and full consent of the intending spouses. (16.2)*
- *Everyone has the right to freedom of opinion and expression (19)*
- *Everyone has the right to freedom of peaceful assembly and association. (20.1)*
- *Everyone has the right to equal access to public service in his country (21.2)*
- **Everyone has the right to rest and leisure, including reasonable limitations of working hours and periodic holidays with pay. (24)**
- *Everyone has the right to a standard of living adequate for the health and well being of himself and his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or lack of livelihood in circumstances beyond his control. (25.1)*
- *Everyone has the right to education. (26.1)*
- *Everyone has duties to the community in which alone the free and full development of his personality is possible. (29.1)*

For the full text please go to the Internet:
<http://www.un.org/Overview/rights.html>

Women's group, organic vegetable growing, literacy, nutrition and skills training have a lot in common and will increase the quality of the women's group. The challenges to be addressed by the self-help education series are that 800,000 children in Zambia do not go to school, scores of youth have no access to skills training or sports education, many youth and adults are illiterate and many women do not know how to find information about how to earn more money to the family. Some people starve, as they cannot afford inputs to grow enough vegetables and many people affected by HIV/AIDS need support and acceptance by the community and many children are malnourished.

The intention of distributing the 16 resource manuals to the places where there are no education is to provide information and encouragement for fully sustainable self-help education projects of community priority.

About The Manual

The manuals empower communities to initiate self-help educational activities, which are planned and implemented by the local people. We believe that sustainable development initially must mobilise peoples' own human- and environmental resources, therefore we offer simple capacity building resources manuals.

A good start would be to hold a sensitisation meeting called by the local Chief that provides a dialogue with the local community members that assesses both the felt needs for education and establishes the opportunities to satisfy the needs. This meeting identify volunteer teachers, trainers and resource persons in the community, and organise committees that will be responsible for the education project. Secondly, the community needs detailed information about available resources concerning the chosen education project in order to implement the plans solely on self-help. Therefore the relevant resources manuals are given to the leaders' as such knowledge is not easily available to the people from other sources.

The manuals are written in English for Zambian community and Church leaders. Many community members are illiterates, reading neither English nor a local language. However, most places there are at least a few people that read English and they will be able to interpret the manuals to their fellow community members. Therefore, we do not see any benefit of translating and printing the manuals in the vernaculars.

The teaching that the above self-help initiatives are capable of organising is not quality education. However, the advantages of such initiatives are to provide basic teaching by volunteer instructors while waiting for the Government to take over the responsibility for education. Then the self-help education initiatives make the educational needs visible and quantitative to the Government and the donors.

The method is a simple combination of encouragement and factual information

These decisions really go hand in hand with your strategic planning process, and you will need to go back time and again to reflect on how well things are working.

Things to think about, in the support group when beginning to form partnerships or networks, include:

It is important to appoint a person or small team that will take responsibility for coordinating the process, calling meetings, and making sure things are happening. Normally this is a person or group who is passionate about getting things done and is also a practical thinker and a 'doer'.

This chapter is edited from the book "The Church in an HIV+ World"

Working Successfully with Volunteers

It is important to remember that volunteers are more than just a source of free labour! They are a valuable, in fact a vital, part of your organisation, and need to be treated as such.

When appointing a volunteer, consider the following:

It is imperative to screen prospective volunteers carefully. Those applying to be volunteers might have different motivations, one of which might be the hope that they will one day become employed by the organisation for which they are volunteering. Or they might just be bored and looking for something to do, without being really committed to the vision or values of the work.

For these reasons, the best recommendation is probably that the person is already doing similar work to what you would like them to do in your project.

Take into account the needs of your volunteers. Unlike volunteers in Europe and the USA, most volunteers in disadvantaged communities in Zambia are unemployed people who have decided to use their time profitably rather than wasting their days away. This means that often they do not in fact have any other source of income. Consider some sort of incentive or reward to help them meet their own needs and those of their families.

Even though they might not be officially employed, it is helpful to have volunteers sign a type of contract agreement, which outlines clearly the following:



- Job description
- Expected times or hours of work per week or month.
- Training they will receive and be expected to complete successfully.
- Nature of reporting requirements (usually a specific reporting form is helpful, as it provides a clear framework in advance for the type of information your church / organisation will need).
- And support offered such as reimbursement of taxi fare claims or telephone charges or use of a cell phone.
- Incentives or rewards such as food or periodic cash gifts. If you have no incentives/ rewards to offer, say so clearly in your contract, to avoid a mismatch in expectations.
- Spiritual support offered (indicate if your church / organisation has a minimum number of spiritual or other counselling sessions or retreats in which volunteers might be expected to participate).

Remember to let the volunteers know regularly how much you appreciate them. This might be done in a letter, in which you outline the numbers of hours worked, tasks completed, and numbers of people who have benefited from their faithful service (based on their reports to you, and perhaps comments from some of the people with whom they have worked). Then offer your thanks and perhaps a scripture or other word of affirmation and encouragement. *This chapter is quoted from the book "The Church in an HIV+ World"*

Emotional and Spiritual Care and Counselling For the Person with AIDS

Being tested HIV+ can have a major impact on someone's life. However, many people are able to continue with a normal life after a positive diagnosis. They are more aware of their physical and health status and are concerned with minor illnesses and blood test results.

With the onset of AIDS symptoms the person enters a whole new phase, both on a physical and an emotional level. Physically the disease progresses in four phases:

Acute phase or acute seroconversion illnesses (Glandular fever-like illnesses)

Asymptomatic carrier stage (The person displays no symptoms)

Early symptoms of HIV disease (Tiredness, fever night sweats, diarrhoea, oral thrush, shingles and neurological changes are common symptoms)

AIDS (Minor symptoms of HIV disease become more serious and persistent. The person is thin and emaciated, exhausted most of the time and suffers persistent opportunistic infections such as Kaposi's sarcoma, tuberculosis and pneumonia).

Community Self-Help Education Series Empowering Communities

The "Community Self Help Education series" published by Response Network have available 16 self help education manuals for use by Church & community leaders.

- 1 "Let's start our own Community School".
- 2 "Let's start our own community sports club".



- 3 "Let's start our own Community Literacy class"
- 4 "Let's start our own Community Skills Training"
- 5 "Let's start our own women's group"
- 6 "Organic Vegetable Growing"
- 7 "Let's start our own HIV/AIDS Support Group."
- 8 "Let's start our own community health and nutrition club."
- 9 "Let's start our own know your rights club"
- 10 "Let's start our own community alcohol awareness and support group".
- 11 "Let's start our own community mental health club"
- 12 "Let's start our own community participation (governance) club"
- 13 "All included" Let's start our own community support group for children with special needs'.
- 14 "Let's start our own Community Women's Rights Club – Stop the Violence"
- 15 "From team to Inclusive Sports Club."
- 16 "The Gender Equality in Governance Club"

The manuals supplement each other so you will benefit from combining the resources from two or more manuals to increase the quality of your education project. For instance literacy and skills training are like brother and sister because skills training make literacy lessons more meaningful and relevant to the adult learner.

Organic vegetable growing, sports club and HIV/AIDS support group can enhance the work of the nutrition club as they are supplementing each other.



There is a parallel emotional progression, which is accompanied by distinctive human needs.

It is important to note that many of these feelings appear in different stages of the disease. Each of the human needs, therapeutic interventions and spiritual needs can therefore also appear in other phases. *This chapter is quoted from the book "The Church in an HIV+ World"*



Ask for support

The committee may request for the following assistance to the work of the HIV/AIDS support group, however you have to be vigilant and ask now and again, as you will not get anything unless you are persistent and keep pushing!

Make your request to the **District Health Medical Board office** through the Community AIDS Task Force (CATF) to invite your support group members for free **courses** in subjects such as caring, counselling, support, health and awareness that they can connect your HIV/AIDS support group to. The District Health Board sometimes has support in form of funds, materials, medicines or food to offer the HIV/AIDS patients in the community, – ask what they have to offer. They are linked to other providers such as:

The District Hospital and some Health Centres

Hospitals and health centres distribute ARV's Anti Retro Viral drugs to the AIDS patients. Find out from the health staff in the district where you can advice the AIDS patients to go for ARV medication. The prevention of mother to child transmission (PMTCT) treatment is also available and get advice from the

Abbreviations

Aids	Acquired Immune deficiency syndrome
ARV	Anti Retro Viral
CATF	Community AIDS Task Force
DHBS	District Health Board Secretary
GRZ	Government of the Republic of Zambia
HACI	Hope for African Children Initiative
HIV	Human Immuno Virus
NGO	Non Governmental Organisation
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child transmission
OVC	Orphans and Vulnerable Children
Scope OVC	Strengthening Community Partnership in Empowering Orphans and Vulnerable Children
STI	Sexual transmitted infections
SWAAZ	Society for Women and AIDS in Africa Zambia
UNICEF	United Nations Children's Fund
WFP	World Food Programme
USA	United States of America

PROGRESSION OF DISEASE	EMOTIONAL EXPERIENCE	HUMAN NEED	FOCUS OF COUNSELLING	SPIRITUAL FOCUS
1. Diagnoses	Denial, fear, anxiety	Security	Empathy	God's compassion (Trust)
2. Symptomatic Phase (Health Impairment)	Isolation, loneliness, mourning	Connection	Communication and relationships	Belonging to a healing community, acceptance
	Guilt (Internal & External) remorse, anger	Forgiveness	Restitution	Reconciliation (with self, others and God)
3. Full blown AIDS (Severe Health Impairment)	Self-rejection, depression, hopelessness, worthlessness	Dignity	Hope and meaning	A hopeful and meaningful life
4. Terminal Phase	Wasting away, uncertainty, fear	Peace and acceptance	Letting go	Peace
5. Bereavement	Sadness and longing, anger, depression	Grieving the loss	Acceptance of loss, continuing with life	Comforting

Health

Register the HIV/AIDS support group with the District health medical board office, so you get advice, support and teaching about nutrition, hygiene, HIV/AIDS awareness, (STI) sexual transmitted infections and condom use. Then you will also benefit from health talks, that they may conduct for the HIV/AIDS support group members. HIV/AIDS support groups should make partnership with the nearest health centre.

Production unit

It is useful for the HIV patients in the community to learn agriculture. Make sure you get some land for the production unit for use by the HIV/AIDS patients. The District Council or the local Chief will lend you land for free to use for this purpose. Even growing vegetables on small areas around the house in the back yard will give something in the pot every day. Engagement in agriculture will give the HIV patients in the community both a good learning opportunity and produce food for consumption. District Agricultural Office and the extension officer will give you advice and support to do the right things considering the quality of the soils, pests, seeds etc.

Follow up the initiatives!

Note that whenever applying for support somewhere, - make follow up enquiries by personal visit or by telephone to find out if the letter was received, - or may be you omitted some important information so the application is not attended to. If you are not used to writing an application, seek advice from partners you trust, look for one among those we have mentioned earlier on. We wish you good luck in the very noble task of providing support to the HIV/AIDS patients in the community. You will succeed by going step by step, - and this journey will surely take you very far.

Do you need more coaching?

If you get stuck somewhere in the process of developing the HIV/AIDS support group, or you feel that the assistances we have recommended to you, are disappointing you, – you are welcome to contact the writer of this manual: Arnfinn Solli, Email: sarnfinn45@gmail.com or mail@responsenetwork.org and we will reply to the questions as soon as possible. If you have good experience of getting assistance we would like to hear from you about that as well to commend those partners in the next edition.

or the District Social Welfare offices in your District.

PRIDE Zambia

PRIDE gives loans to small scale enterprises. The organized club can apply from them. Email: pride@zamnet.zm

United Nations

Offers human rights information. Information can be obtained on <http://un.org/Overview/rights.html>

LOCAL AUTHORITIES/COUNCILS

Offices of District AIDS Coordination Advisor provide information on HIV/AIDS Response in the Districts.

Support in kind

Used and rehabilitated Tools delivered free

When a support group decides to facilitate some income generating activity, this donor may supply the tools the support group needs. Gered Gereedschap can deliver tools for the following vocational trades: carpentry and joinery, metalwork, Auto-mechanics, building and construction, electrical engineering, sewing. Considered are applications submitted by locally organised projects that focus on income generation, self-sufficiency and/or employment creation. Individuals or large projects cannot apply. Extra preference is given to projects that pay attention to the position of the HIV patients in the community, marginalized groups, ecological awareness and/or environmental protection. Gered Gereedschap mainly delivers hand-tools and small electrical equipment. The amount of tools that can be provided depends on available stock and has a minimum of one cubic meter (1m³).

Before you apply, make partnership with an organisation or a church in your Church and community or MYSCD that is non profit and exempt the import. Make sure that the import papers are issued in the name of the partner organisation or MYSCD (Ministry of Youth, Sport and Child Development) that is -exempt. An application can be submitted by answering the general questionnaire of Stichting Gered Gereedschap.

This questionnaire is available on request and has to be answered in as much detail as possible. STICHTING GERED GEREEDSCHAP, (SAVED TOOLS FOUNDATION), PO Box 3767, 1001 AN Amsterdam, M.van Bouwdijk Bastiaansestraat 58, 1054 SP Amsterdam, Netherlands, Tel. +31 (0) 402 852 705, E-mail: info@geredgereedschap.nl

district health staff.

SOURCES OF HELP FOR HIV AND AIDS INFECTED PEOPLE

From the Government, infected people get funding for projects and also free ARV drugs to boost the immunity of people.

The Government of the Republic of Zambia (GRZ) has deployed a multispectral response to HIV/AIDS by adopting one national AIDS strategic framework 2006-2010; one national coordinating body, the National HIV/AIDS/STI/TB Council (NAC) reporting to a cabinet committee on AIDS with decentralized structures; and one monitoring and evaluation system. The GRZ has integrated HIV into the development agenda with the objective: To halt and begin to reverse the spread of HIV and mitigate its impact. The response has aimed to prevent viral transmissions, care for those infected and their relatives/dependents, and reduce the personal, social and economic impact of AIDS. National Institutes of Health Manuscript, July 28, 2011.

From Non-Governmental Organizations, they can get materials such as condoms for protection and food items:

AIDS Healthcare Foundation Zambia

The foundation offers high quality antiretroviral treatment, ...HIV/AIDS; Advocacy/Take Action; Medical Services; Research; Global Programs; Media Center; At Chikankata mission hospital in Southern Province of Zambia. Details can be obtained from <http://www.aidshealth.org/africa/zambia>

World Health Organization (WHO)

Helps in Early infant diagnosis of HIV infection in Zambia and in Southern Province as well. Details can be followed on <http://www.who.int/bulletin/volumes/90/5/11-100032/en/>

Oxfam Zambia

Oxfam supports the poor to improve their standard of living in the community, development and education in Copperbelt, Northern, and Southern, Western, Central, Eastern and Lusaka Provinces. Plot 250 Zambezi Road, Roma, Lusaka. P.O. Box 35624, Lusaka. Tel. 0211 292 070/0211 291 518, Email: oxfam@zamnet.zm

World vision

World vision supports Church and community development projects all over the country. Plot No. 51/52 Great East Road, Lusaka. Tel. 0977 771 402. P. O. Box 31083, Lusaka.

Institute of Cultural Affairs

Institute of Cultural Affairs is concerned about providing training in household and community food security, water, sanitation and micro-credit. P. O. Box 31454, Lusaka. Tel No 01 25 22 93. E-mail: icazam@zamnet.zm

World Food Programme (WFP)

Is concerned with the supply of food to people living with HIV and AIDS. Procedure can be obtained from WFP by Tel. 01 225 423, P.O. Box 31966, Lusaka